

# Problems and hopes perceived by mothers, fathers and physicians of children receiving palliative care

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## Abstract

**Background** The quality of shared decision making for children with serious illness may depend on whether parents and physicians share similar perceptions of problems and hopes for the child.

**Objective** (i) Describe the problems and hopes reported by mothers, fathers and physicians of children receiving palliative care; (ii) examine the observed concordance between participants; (iii) examine parental perceived agreement; and (iv) examine whether parents who identified specific problems also specified corresponding hopes, or whether the problems were left 'hopeless'.

**Method** Seventy-one parents and 43 physicians were asked to report problems and hopes and perceived agreement for 50 children receiving palliative care. Problems and hopes were classified into eight domains. Observed concordance was calculated between parents and between each parent and the physicians.

**Results** The most common problem domains were physical body (88%), quality of life (74%) and medical knowledge (48%). The most common hope domains were quality of life (88%), suffering (76%) and physical body (39%). Overall parental dyads demonstrated a high percentage of concordance (82%) regarding reported problem domains and a lower percentage of concordance on hopes (65%). Concordance between parents and physicians regarding specific children was lower on problem (65–66%) and hope domains (59–63%). Respondents who identified problems regarding a child's quality of life or suffering were likely to also report corresponding hopes in these domains (93 and 82%, respectively).

**Conclusion** Asking parents and physicians to talk about problems and hopes may provide a straightforward means to improve the quality of shared decision making for critically ill children.

## Introduction

Paediatric palliative care patients typically live for more than a year, unlike adult palliative care patients who on average die within days or weeks.<sup>1</sup> During this lengthy time period, parents of children receiving palliative care often face difficult and emotionally charged decisions about their child's medical care, including whether to institute a limit of intervention order (such as a Do Not Attempt Resuscitation order), whether to start a new form of technology-based care (such as tracheostomy or a mechanical ventilator) or whether to enrol in a clinical trial. The prevailing model of medical decision making for adults with serious illness emphasizes individual autonomy, ignores relational aspects of decision making and omits key emotional aspects of these decisions.<sup>2,3</sup> Most paediatric palliative care decisions, however, are made jointly between mothers, fathers and physicians as opposed to a single autonomous decision maker.<sup>2-6</sup>

The medical decision-making process of married or partnered couples has been examined in prior research. When one spouse faces a health problem, such as prostate cancer<sup>7</sup> or arthritis pain,<sup>8</sup> concordance between spouses on problems associated with the health condition predicts health and emotional outcomes for both spouses. Less is known regarding concordance between spouses when making medical decisions for a child. Among parents of children with terminal cancer, couples may differ in their ratings of their child's quality of life and may consider different factors when deciding between aggressive treatment and palliative care.<sup>9</sup>

Some research has found that better communication between physicians and patients correlates with better outcomes and higher patient satisfaction.<sup>10-12</sup> Parents and health-care providers, however, sometimes report communication problems and disagreements about priorities and treatment approaches for terminally ill children.<sup>13</sup> For children dying of cancer, significant delays exist between the physician realization that the child is unlikely to recover and parents reaching the same reali-

zation.<sup>14</sup> In addition, parents' and physicians' perceptions of the child's symptoms (including pain and suffering) may differ significantly,<sup>15</sup> as can their priorities when choosing aggressive treatment or palliative care.<sup>5</sup> Some parents report concerns about losing support from the medical team over such disagreements.<sup>6</sup> These findings suggest that physicians and parents of dying children may perceive situations very differently, which has important consequences for the decision-making process.

As part of paediatric palliative care, parents are often asked questions about what they think are the most important problems in the child's care and what their hopes are for the child, but these responses have not been systematically studied (except for endorsement of symptoms using checklists).<sup>15</sup> Furthermore, in shared decision making, there is ideally a common perception of the problems the patient faces and what the family hopes to achieve.<sup>16</sup> If concordance is high, parents would report similar kinds of problems and hopes with each other, and the child's physician would report similar problems and hopes compared with each parent. This shared or collaborative aspect of decision making – which we call *observed concordance of problems and hopes* – is not well described or appreciated.

Most prior studies of concordance or agreement have used scales developed to measure agreement on specific symptoms or concepts like quality of life and health utility and compared parents and physicians. While these comparisons provide useful information, they may not capture key aspects of how the parents and physicians are thinking about the child's situation, especially if there are no questions that focus attention on particular issues. To our knowledge, parental responses to open-ended questions about problems and hopes have not yet been reported in a paediatric palliative context, yet these responses can address important issues. For instance, what problems and hopes are identified by parents (including single parents) and physicians involved in the care of a child? When more than one parent is involved in making decisions for the child, is there con-

cordance or overlap in the themes of the problems and hopes identified by the parents? How much concordance or overlap is there between the parent(s) and the physician? And do parents who identify specific problems also identify hopes specific to that problem or are some of their identified problems left 'hopeless'?

We therefore explored perceptions of problems and hopes by asking parents and physicians of children with life-threatening conditions receiving palliative care two open-ended questions about what problems they saw the child facing and what their hopes were for the child. Specifically, we aimed to (i) describe the problems and hopes reported by mothers, fathers and physicians caring for children receiving palliative care; (ii) examine the observed concordance between participants on reported problems and hopes for a given patient; (iii) examine the parents' perceived agreement about problems and hopes with each other and with the physician; and (iv) examine whether the problems identified by an individual are paired with corresponding hopes.

## Methods

### Study information

This study was part of the Decision-making in Pediatric Palliative Care study conducted from October 2006 to July 2008 at the Children's Hospital of Philadelphia (CHOP).<sup>17,18</sup> CHOP's Committee for the Protection of Human Research Subjects approved the protocol for this study.

### Participants and procedures

The families of children receiving new or existing palliative care consults were recruited from inpatient units at CHOP. Patients are referred for palliative care consults by generalists and subspecialty paediatric services for decision support, pain or symptom management and potential coordination of hospice services. Parents of patients were approached at the patient's bedside by research team members

who were not clinicians and not involved in patient care activities, informed of the purpose of the study, and asked if they were interested in participating. Parents were eligible to participate if they spoke English and made medical decisions for the patient because the patient was under 18 years of age or cognitively impaired. Eligible parents were consented and participated in a semi-structured interview. Each parent was asked whether there was a second parent who helped in making decisions. If the second parent was available and interested in participating, they were consented. Each parent completed the interview separately. Most parents were enrolled and completed the interview in person at the child's bedside. Some parents completed the interview at a later time after the patient had been discharged from the hospital. The parents were asked to identify the doctor most involved in the child's care. We relied on parent report, even if the physician identified did not have primary medical responsibility for the patient. Physicians were contacted by phone and consented verbally. We asked each parent and physician to identify the three problems and three hopes most relevant to the child's health. Two of the authors (KC and KH) conducted all interviews which were audio recorded and subsequently transcribed.

### Measures

#### *Parent and child characteristics*

Parent age, type (mother, father or other), race (White, African American or more than one race), ethnicity (Hispanic or Non-Hispanic), education (high school, some college/college graduate or some graduate school/graduate school graduate) and marital status (married or divorced/separated/single) were obtained via respondent self-report. The child's race, ethnicity and insurance status (private, Medicaid or low cost/limited/none) were also obtained via respondent self-report, while the child's sex, location (hospital ward, intensive care unit or outpatient clinic) and complex chronic condition category (metabolic,

neuromuscular, malignancy, congenital or respiratory) were obtained via medical chart review.

### *Problems and hopes*

As part of semi-structured interview, parents were asked the following open-ended questions: 'Please think of three major problems that bother your child', and 'Please think of three major goals or hopes you have for your child'. Physicians were asked similar questions: 'Please think of the three most significant problems that bother your patient', and 'Please think of the three most significant goals or hopes you have for your patient. Two research team members (KC and CF) initially reviewed a subsample of responses, generating an initial set of categories according to the qualitative analysis method that underlies grounded theory.<sup>19</sup> This method has been used in similar qualitative studies of interview transcripts.<sup>20–22</sup> They applied these categories to all of the responses independently. They met regularly with two other research team members (KH and another qualitative researcher at CHOP) to discuss the categories and the coding process; all discrepancies were resolved through discussion and consensus. This process ultimately yielded 24 categories that were aggregated into eight broader domains applicable to both problems and hopes (See Table 1). For example, the domain 'Medical Knowledge' includes any statements that fit in the following categories: certainty or uncertainty, understanding of trade-offs, medical information and decision-making confidence. Many problems assigned to this domain refer to being frustrated at the lack of certainty about the child's exact diagnosis. Hopes often referred to hoping that better information would be available in the future. More complex problems and hopes could be assigned to more than one domain, so participants could potentially have more than three domains of problems or hopes. For example, 'I hope my child stops being in pain so he can go home' was placed into 'Suffering' and 'Quality of Life' because the parent directly mentioned pain and thought the child would have a better quality of life at home.

The coders separately assigned each response in the subsample to one or more domains and then met to discuss any disagreements and achieve consensus.

### *Observed concordance of problem and hope domains*

To assess observed concordance or overlap in the problem and hope domains, we matched the responses for each patient (e.g. the problems and hopes that a mother, father and physician reported for a particular patient). We divided the number of matched domains (problems or hopes) between two groups of respondents (e.g. the mother and father) by the total number of the first respondent's (e.g. the mother's) domains and separately by the second respondent's (e.g. the father's) reported domains. This yielded an observed concordance percentage between the two respondents for that particular patient. Note that if two participants cited distinct problems for the patient, and the problems were classified into the same domain, then these problems were coded as a match. We then calculated the mean observed concordance across the patients for each subgroup (mothers and fathers, mothers and physicians, fathers and physicians).

### *Reported agreement*

Parents were asked to rate their agreement with four statements 'I and [child's other parent] agree about our child's most important problem'; 'I and [child's other parent] agree about our child's most important goal or hope'; 'I and my child's managing physician agree about our child's most important problem'; 'I and my child's managing physician agree about our child's most important goal or hope.' The response options for each statement ranged from 1 = 'Strongly Disagree' to 5 = 'Strongly Agree'.

### *Problem and corresponding hope domains within individuals*

We assessed how often respondents who reported a given problem domain also reported a corresponding hope domain.

**Table 1** Problem and hope categories and domains

Eight problem/ hope domains	24 Categories	Problem examples	Hope examples
Miracle or cure	Miracle or cure	Parent: 'The tumour is back and there is no cure' Physician: 'There are no cure options to offer the family'	Parent: 'Beat the mitochondrial disease' Parent: 'To be normal again, active, involved in school'
Length of life	Longer or shorter life	Parent: '[My child] has limited time left' Physician: 'Very poor prognosis'	Parent: 'To have a longer, healthier life' Physician: 'Extend his time here as long as possible'
Physical body	Improved organ performance, Physiological stability	Parent: 'Airway occluded and needs a [tracheostomy]' Physician: 'Severe CNS/brain disease'	Parent: 'That her arteries improve' Physician: 'Get rid of scalp accumulation of fluid'
Medical care	Coordination of care, adherence, delivery of care, treatment options	Parent: 'Feels like we're just putting out fires'  Physician: 'No known treatment'	Parent: 'To give her good care to help her as much as possible'  Physician: 'Improved symptom management for both the nausea and depression'
Medical knowledge	Certainty or uncertainty, understanding of trade-offs, medical information, decision-making confidence	Parent: 'Not knowing the diagnosis of the tumour' Physician: 'Finding the reason or cause for the spasms/movements'	Parent: 'To have the necessary tools and equipment' Physician: 'That her parents can gain a better understanding of the severity of the disease'
Suffering	Pain and non-pain	Parent: 'Frequent blood draws are painful' Parent: 'Reflux causes pain' Physician: 'Pain control'	Parent: 'Minimize mental and physical suffering' Physician: 'Keep as comfortable as possible'
Quality of life	Relationships with family, openness, At home or elsewhere, specific achievement, enjoyable activities, peacefulness, education	Parent: 'Difficult to communicate' Physician: 'Not enjoying life'	Parent: 'Happiness' Parent: 'Get back into school' Physician: 'That he have the best QOL possible'
Meaning	Spiritual or religious, meaning or purpose, not defiling, advocacy	Parent: '[My child] feels that life is leaving her behind' Parent: '[My child] keeps saying she's sorry for relapsing'	Parent: 'To have a rich, fulfilling and safe life' Physician: 'For someone to talk with the child and provide emotional and spiritual guidance'

## Statistical methods

Not all families had each of the three types of respondents (mother, father and physician). We therefore conducted some analyses across all 110 participants and conducted other analyses subgroups of families with matching data for mothers and fathers ( $n = 21$ ), mothers and physicians ( $n = 36$ ) and fathers and physicians ( $n = 20$ ).

We used paired *t*-tests within the subgroups to compare the mean number of problem and hope domains (e.g. total number of problem domains and total number of hope domains) reported by the different kinds of participants (mothers, fathers and physicians). We then report the frequency of specific problem and hope domains (e.g. miracle or cure, length of life, etc.) for the entire sample ( $n = 110$ ) including families where only one parent completed the interview ( $n = 7$ ) or one parent and a physician completed the interview ( $n = 22$ ). We compared the distribution of different (problems or hopes) domain categories between subgroups using frequency tables and reported *P*-values from Fisher's exact test. The analyses of observed concordance and reported agreement were conducted with paired *t*-tests to compare specific measures between the subgroups (mother and fathers, mothers and physicians, fathers and physicians).

For the separate measure of reported agreement (the scale items), we used Spearman rank-order correlation to examine the relationships between the subgroups.

Although some physicians were in the sample more than once, they were treated as independent observations as they completed each interview separately and reported problems and hopes unique to each patient. All *P*-values represent two-sided hypothesis tests, and a significance level of 0.05 was set for all tests. All analyses were conducted with Stata 12.1 (StataCorp, College Station, TX, USA).

## Results

Of the 88 families eligible to participate, 50 families agreed to participate (63% response

rate) with at least one parent interviewed. Data were obtained from a second parent for 21 families for a total of 71 parents: 44 mothers (62%), 25 fathers (35%), one stepmother (1%) and one grandmother (1%); in our analyses, the stepmother and grandmother were classified as mothers. Where one parent participated ( $n = 29$ ), the respondent was the child's mother ( $n = 24$ ) or father ( $n = 4$ ). Thirty-four physicians agreed to participate in the study and were interviewed about 39 patients. Three patients died before the physician interviews could be completed. For the remaining eight patients, the physician did not respond to requests for an interview.

The 50 patients (Table 2) ranged in age from newborn to 24 years (median = 4 years with interquartile range = 6.17) with the majority (96%) <18 years old. The most common diagnoses were neuromuscular disorder (28%), metabolic disorder (26%), malignancy (20%) and congenital disorder (18%). The 71 parents (Table 3) ranged from 21 to 66 years of age (mean = 36.8,  $s = 7.7$ ). The 34 physicians (Table 3) were slightly more likely to be male and were predominately non-Hispanic Caucasians.

## Problems

Responses were classified into a mean of 2.9 problem domains per participant ( $s = 1.2$ , range 0–6). The mean number of problem domains did not differ between mothers, fathers and physicians (means ranged from 2.9 to 3.3, all *P*'s > 0.05). From most to least common among all 110 respondents, the domains were physical body (88%), quality of life (74%), medical knowledge (48%), suffering (46%), medical care (23%), miracle or cure (7%), length of life (4%) and meaning (3%). Although there were no significant differences in the frequency of problem domains between mothers ( $n = 46$ ), fathers ( $n = 25$ ) and physicians ( $n = 39$ ; all *P*'s > 0.14), there were some non-significant differences in the patterns of problems across types of respondents. Mothers,

**Table 2** Demographic and clinical characteristics of 50 children

	No. (%)
Age (years)	
1 or less	13 (26)
1–4	15 (30)
5–9	11 (22)
10–17	9 (18)
18–24	2 (4)
Sex	
Female	27 (54)
Male	23 (46)
Race	
White	32 (64)
African American	11 (22)
More than 1 race	3 (6)
Asian	1 (2)
Not reported	3 (6)
Ethnicity	
Hispanic	4 (8)
Non-Hispanic	43 (86)
Not reported	3 (6)
Insurance	
Private	20 (40)
Medicaid	23 (46)
Low cost/limited/none	3 (6)
Not reported	3 (6)
Location at time of interview	
Hospital Ward	24 (48)
Intensive Care Unit	15 (30)
Step down ICU	1 (2)
Outpatient Clinic	3 (6)
Home	7 (14)
Complex Chronic Condition	
Metabolic	13 (26)
Neuromuscular	14 (28)
Malignancy	10 (20)
Congenital	9 (18)
Respiratory	2 (4)
GI	1 (2)
Cardiovascular	1 (2)

fathers and physicians were all most likely to mention problems in the physical body (85, 100 and 85%, respectively; Fig. 1) and quality of life domains (74, 80 and 69.2%, respectively). The third most common problem domain for mothers (47%) and fathers (44%) was suffering, whereas the third most common problem domain for physicians was medical knowledge (62%). In addition, physicians were more likely to mention problems related to

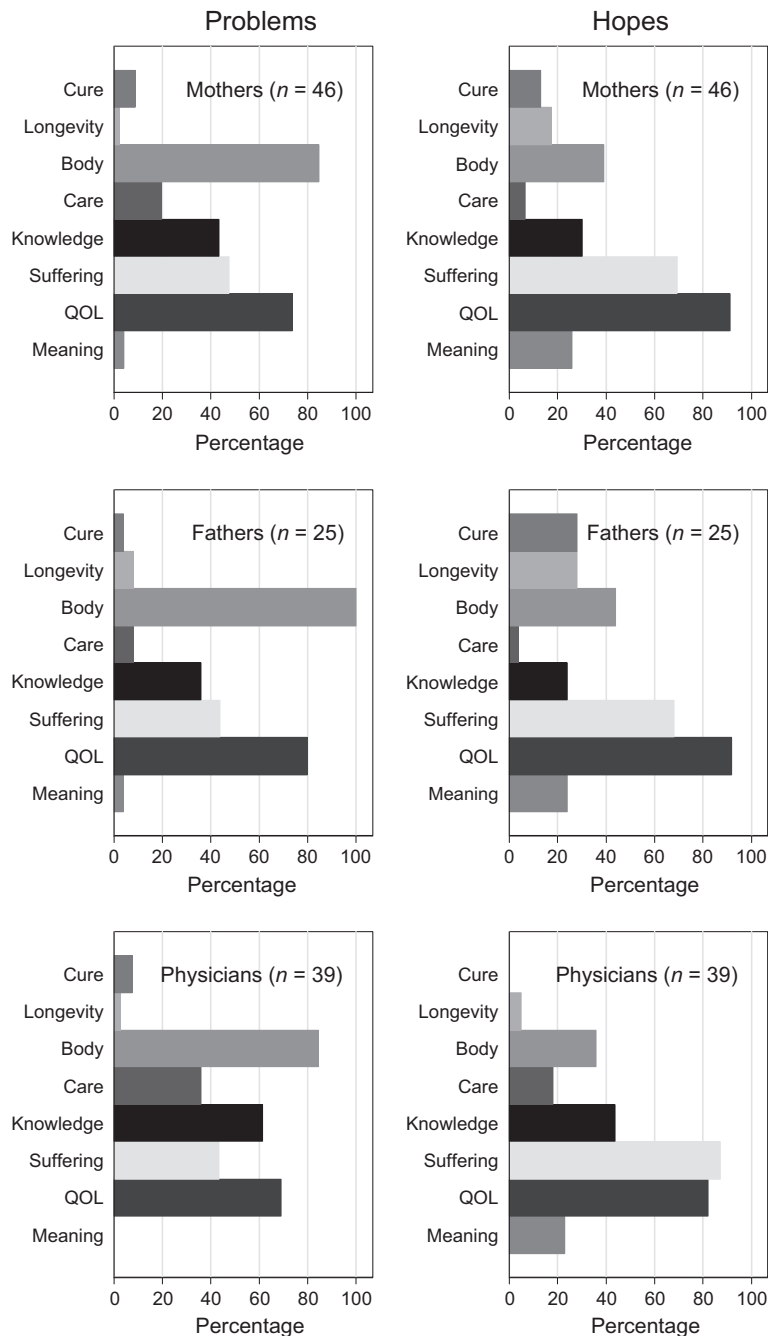
**Table 3** Demographic characteristics of 71 parents and 34 physicians

	No. (%)
<i>Parents</i>	
Age (years)	
21–34	23 (32)
35–38	21 (30)
39–66	24 (34)
Not reported	3 (4)
Type	
Mom	44 (62)
Dad	25 (35)
Other	2 (3)
Race	
White	52 (73)
African American	9 (13)
Asian	1 (1)
More than 1 race	4 (6)
Not reported	5 (7)
Ethnicity	
Hispanic	5 (7)
Non-Hispanic	61 (86)
Not reported	5 (7)
Education	
High school	14 (20)
Some college or college graduate	32 (45)
Some graduate school or graduate school degree	15 (21)
Not reported	10 (14)
Marital status	
Married/Partnered	52 (73)
Divorced/separated/widowed	10 (14)
Single	7 (10)
Other/not reported	2 (3)
<i>Physicians</i>	
Sex	
Male	18 (53)
Female	16 (47)
Race	
White	30 (88)
Asian	4 (12)
Ethnicity	
Non-Hispanic	34 (100)
Specialty	
Oncology	9 (26)
General paediatrics	5 (15)
Adolescent medicine	1 (3)
Anaesthesia/Critical care	4 (12)
Cardiology	3 (9)
Child Development, rehabilitation and metabolic	1 (3)
Metabolism	2 (6)
Neonatology	1 (3)
Neurology	5 (15)

**Table 3.** Continued

	No. (%)
Neurosurgery	1 (3)
Pulmonary	1 (3)
Resident/Other	1 (3)
Palliative Care Team Member	5 (15)

medical care (36%) than mothers (20%) and fathers (8%). No physicians listed any problems associated with meaning, whereas two mothers (4.3%) and one father endorsed this domain.

**Figure 1** Percentage of mothers, fathers and physicians reporting each domain of problems and hopes.

## Hopes

Responses to the hopes question were classified into a mean of 3.0 hope domains per participant ( $s = 1.2$ , range 0–6). The mean number of hope domains did not differ between mothers, fathers and physicians (means ranged from 2.9 to 3.3, all  $P$ 's  $> 0.05$ ). Hope domains most commonly mentioned by all respondents were quality of life (88%), suffering (76%), physical body (39%), medical knowledge (33%), meaning (25%), length of life (15%), miracle or cure (12%) and medical care (10%). The frequency of hope domains for fathers was significantly different than the frequency of hope domains for physicians ( $P < 0.01$ , Fig. 1). In particular, fathers were more likely than physicians to endorse hopes in the miracles or cures domain (28 and 0%, respectively,  $P < 0.01$ ) and in the length of life domain (28 and 5%, respectively,  $P < 0.05$ ). There were no significant differences between mothers and fathers ( $P = 0.88$ ), and there was a marginal difference between mothers and physicians ( $P = 0.09$ ).

## Observed concordance of problem and hope domains between parents

For patients with responses from both the mother and the father ( $n = 21$ ), a high mean percentage of concordance (82%) existed between parents on reported problem domains (Table 4). No significant difference in the degree of overlap was found between mothers and fathers. The overall mean percentage of concordance between parents on hope domains (65%) was significantly lower than the mean concordance for problem domains [82%,  $t(41) = 3.1$ ,  $P < 0.01$ , Table 4]. The patterns of concordance on hopes were similar, and the difference between the mothers (63%) and fathers (67%) was not significant [ $t(20) = 0.55$ ,  $P = 0.59$ ].

## Observed concordance of problem and hope domains between parents and physicians

For patients with responses for both the mother and the physician ( $n = 36$ ), the overall

**Table 4** Observed problem and hope concordance

	Problems (%)	Hopes (%)
Parental concordance		
Overall overlap between parents ( $n = 21$ )	81.5	64.8
Mother domains overlapped by father	77.8	62.9
Father domains overlapped by mother	85.2	66.6
Mother and Physician Concordance ( $n = 36$ )		
Overall overlap between mother and physician	66.1	63.3
Mother domains overlapped by physician	66.7	63.1
Physician domains overlapped by mother	65.6	63.4
Father and Physician Concordance ( $n = 20$ )		
Overall overlap between father and physician	69.2	56.0
Father domains overlapped by physician	70.8	56.7
Physician domains overlapped by father	67.7	55.3

mean percentage of concordance between mothers and physicians on reported problem domains (63%) was lower than the concordance for problem domains between parents (82%) (Table 4). There was no significant difference between how much mothers' problem domains were overlapped by the physicians' problem domains and how much the physicians' problem domains were overlapped by the mothers' problem domains. The results were similar for concordance between the fathers and the physicians ( $n = 20$ ). The concordance patterns between parents and physicians on hope domains were similar to the concordance for problem domains, except that the concordance between fathers and physicians on hopes was lower (55–57%) than the concordance between mothers and physicians (63%) (Table 4).

## Reported agreement on problems and hopes

Reported agreement between mothers and fathers was not significantly associated with observed concordance in problem domains ( $\rho = 0.17$ ,  $P = 0.52$ ) or hope domains ( $\rho = 0.11$ ,  $P = 0.68$ ). Overall, parents reported

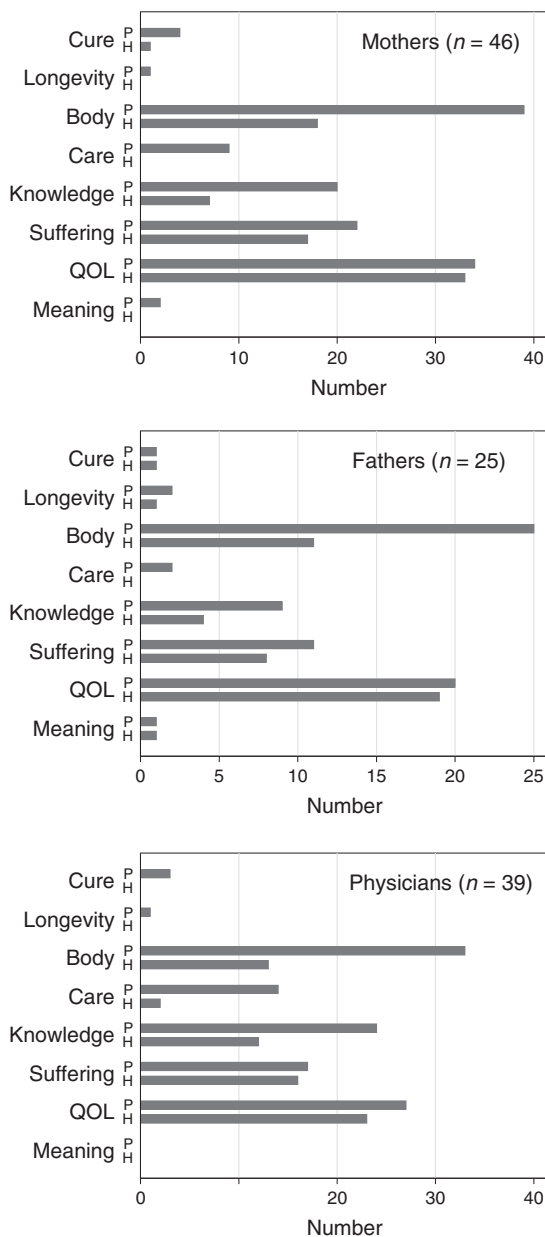
significantly higher levels of agreement with each other about the child's problems (mean = 4.6,  $s = 0.7$ ) than about their hopes for the child [mean = 4.2,  $s = 1.0$ ,  $t(39) = 2.42$ ,  $P < 0.05$ ]. Mothers reported significantly higher levels of agreement on problems (mean = 4.8,  $s = 0.50$ ) than fathers [mean = 4.4,  $s = 0.90$ ,  $t(18) = 2.45$ ,  $P < 0.05$ ]. There were no significant differences between mothers (mean = 4.3,  $s = 1.1$ ) and fathers (mean = 4.2,  $s = 1.0$ ), for reported agreement on hopes.

Reported agreement was also not significantly associated with observed concordance in problem domains between mothers and physicians or fathers and physicians ( $\rho = 0.16$ ,  $P = 0.40$  and  $\rho = 0.07$ ,  $P = 0.79$ , respectively) or with observed concordance in hope domains between mothers and physicians or fathers and physicians ( $\rho = 0.16$ ,  $P = 0.38$  and  $\rho = 0.013$ ,  $P = 0.61$ , respectively).

Compared to their agreement with each other, parents reported significantly lower agreement with the child's physician about both problems [means = 4.6 and 4.0, respectively,  $s = 0.7$  and 1.0, respectively,  $t(39) = 3.77$ ,  $P < 0.001$ ] and hopes [means = 4.2 and 3.8, respectively,  $s = 1.0$  and 1.0, respectively,  $t(40) = 2.53$ ,  $P < 0.05$ ]. There were no significant differences between the mothers (mean = 4.0,  $s = 1.0$ ) and fathers (mean = 4.1,  $s = 1.0$ ) on reported agreement with doctors about problems or hopes (means = 3.9 and 3.7, respectively,  $s = 1.1$  and 0.9, respectively).

#### Problem and corresponding hope domain frequency

For participants who reported a given problem domain, the percentage who reported a hope that matched that problem was 93% for quality of life ( $n = 81$ ), 43% for physical body ( $n = 97$ ), 82% for suffering ( $n = 50$ ), 43% for medical knowledge ( $n = 53$ ), 33% for meaning ( $n = 3$ ), 25% for miracle or cure ( $n = 8$ ), 25% for length of life ( $n = 4$ ) and 8% for medical care ( $n = 25$ ). Mothers, fathers and physicians showed similar patterns of problems and corresponding hopes for the more common domains



**Figure 2** Mothers, fathers and physicians who reported a problem domain (P) and a corresponding hope domain (H).

(Fig. 2), but some problem domains endorsed by a small number of participants (miracle or cure, length of life) showed different patterns of corresponding hopes.

#### Discussion

In our study sample, the most common problem domains were the physical body, quality of

life and medical knowledge. Parents were slightly more likely than physicians to report suffering as a problem, and physicians did not mention any problems associated with meaning. The most common hope domains were quality of life, suffering and physical body. Physicians were slightly more likely to report hopes related to medical knowledge compared with the parents. Overall, there appeared to be a greater range in the number of different hope domains endorsed compared with problem domains, and there were more hope domains that were endorsed by only one parent or physician. These findings reinforce the importance of providing quality paediatric palliative care to maintain quality of life, manage symptoms and reduce suffering for children with life-threatening illnesses.

There was a significant difference in the frequency of the hope domains between physicians and fathers. Fathers were more likely than physicians (or mothers) to report hopes related to miracles, cures and longer life. This finding suggests that physicians may need to take particular care when discussing a child's future with the father and be aware that fathers may stay attached to the idea of the child being cured, getting better or living longer.

There were no significant differences between mothers and fathers in terms of observed concordance on problem domains or overlap on hope domains. This suggests that mothers and fathers do not have unique areas of concerns that are not shared by the other parent. The observed concordance between parents for problem domains was significantly higher, however, than the concordance between parents for hope domains. These results suggest that contemplating or discussing hopes for the child's future may be an abstract, ambiguous or arduous task for parents, one that may require greater support by health-care staff with experience helping parents with these decisions. This finding may also reflect the fact that problems are often more specific and concrete (my child has these visible signs or demonstrable symptoms) than hopes (this is what I'd like

to happen for my child in the future). The less concrete and more open-ended nature of hopes was also reflected in the wider dispersal of hope domains that parents endorsed.

The level of observed concordance between parents and physicians was lower for both problems and hopes than between parents. This may be due to role differences: physicians, by virtue of their medical training and commitment to providing medical care, may be quite sensibly more concerned about gaps in medical knowledge and what they can learn to help other patients in the future. Parents, who have responsibility for the well being of their child, may be understandably more focused on their child's suffering. The lower levels of concordance between parents and physicians suggest that better communication is needed between parents and physicians about problems and hopes. For example, while some parents cited hopes for a miracle or cure, no physicians reported such hopes. Some parents may feel an obligation to endorse the hope of a miracle as a parental duty; in contrast physicians may feel that, as professionals, they must be realistic and avoid raising expectations for an unlikely recovery. To communicate effectively with parents, clinicians need to balance the importance of providing accurate information, while also affirming the parents' desire to serve the child well. The lowest observed concordance was between the hopes of fathers and physicians, suggesting again that physicians may need to take particular care when discussing hopes with fathers.

Mothers reported higher levels of perceived agreement with fathers on problems. This finding suggests that there are residual communication gaps between the parents (fathers, perhaps, have opinions about the child's problems that they do not share with the mother). Mothers may be motivated to believe that they are in more agreement with the fathers than they actually are, or feel a need to present a united front as a couple. Highlighting the greater difficulty of communication about hopes, parents reported slightly lower levels of agreement with each other on their hopes for

the child compared with the problems they identified for the child. Compared with their agreement with each other, parents also reported significantly lower levels of agreement with doctors for both problems and hopes. This finding was consistent with the lower levels of observed concordance between parents and physicians.

Although the results for the measures of reported agreement and observed concordance were similar (i.e. higher levels of agreement on problems than hopes, and higher levels of agreement between parents than between parents and physicians), the measures themselves were not significantly correlated. This finding suggests that high levels of perceived agreement on problems and hopes do not necessarily mean that individuals will in fact identify the same domains when talking about problems and hopes.

Parents and physicians who mentioned quality of life and suffering as problem domains were very likely to mention hopes in those domains, suggesting that some problem domains are more likely to correspond to hopes in both parents and physicians (i.e. the hopes expressed were closely related to the problems identified). Other frequently mentioned problem domains, such as physical body and medical knowledge, were less likely to be mentioned as hopes by all participants, suggesting either that both physicians and parents already appreciated that these problems were intractable or that generating hopes in these domains is harder. Therefore, the likelihood that a parent who identified a problem also identified a corresponding hope depended on which problem domains the parent had identified.

These findings should be interpreted with the study's strengths and weaknesses in mind. The study's prospective semi-structured interview allowed parents and physicians to talk about the child's problems and their hopes in their own words, while care was on-going. This enabled us to explore the broader cognitive and emotional factors that may influence the decision process and avoid retrospective biases.

Interviewing each parent and physician separately allowed examination of social aspects of the decision-making process (regarding how much they agreed about problems and hopes), but some parents may nonetheless have been reluctant to voice concerns about the other parent or the health-care providers. The study's sample size did not provide sufficient statistical power for many dyadic comparisons; future research should strive to enrol more parents and employ a longitudinal design to examine how various factors influence parental decision-making over time. The results of this study should not be generalized to parents of hospitalized children who have not been referred for palliative care. In addition, many contextual factors, such as the age of the child, the child's diagnosis and the length of relationship between parents, may influence the perceived problems and hopes as well as the decision-making process.

Interventions to improve communication between fathers, mothers and physicians regarding a child's problems and their hopes for the child may benefit all involved. While parents and physicians do not need to agree regarding all problems and hopes, physicians should be aware that parents may have very different concerns that need to be addressed in an appropriate and supportive way. The child may receive more effective care in a more timely manner if sources of suffering and factors that diminish quality of life are targeted. In addition, parents may be guided in this most difficult of journeys by a more collaborative partnership with the physician and ultimately by a clearer sense of what they are hoping to achieve for their child.

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## Conflict of interest

The authors declare that they have no relevant financial relationships to disclose.

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## Author contributions

All authors participated in the design of the study and interpretation of the data; Kari Hexem, Douglas Hill and Chris Feudtner performed the data analysis; Kari Hexem, Douglas Hill, Jennifer Faerber and Chris Feudtner drafted sections of the manuscript; all authors revised the manuscript for key intellectual content. All authors read and approved the final manuscript. Chris Feudtner had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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